DOCUMENT RESUME

ED 399 753 EC 305 092

AUTHOR Ambler, Lana; Kupper, Lisa, Ed.
TITLE Respite Care. Briefing Paper. Interim Update.
INSTITUTION Academy for Educational Development, Inc., Washington, D.C.; National Information Center for Children and Youth with Disabilities, Washington, DC.
SPONS AGENCY Special Education Programs (ED/OSERS), Washington, DC.
PUB DATE Jun 96
CONTRACT H030A30003
NOTE 9p.; Adapted from a 1989 NICHCY publication called "Respite Care: A Gift of Time."
AVAILABLE FROM National Information Center for Children and Youth with Disabilities, P.O. Box 1492, Washington, DC 20013-1492; telephone: 202-884-8200; toll-free telephone: 800-695-0285; e-mail: nichcy@aed.org.
PUB TYPE Collected Works - Serials (022) -- Guides - Non-Classroom Use (055)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS Child Rearing; Children; *Chronic Illness; Coping; *Delivery Systems; *Disabilities; Family Needs; Family Relationship; Federal Legislation; Financial Support; Parent Child Relationship; Parent Role; Resources; *Respite Care

ABSTRACT

The challenges that families face in caring for a child with a disability or a chronic illness are reviewed in this report on respite care. A parent's narrative describes the difficulties in providing around-the-clock care to a child with a chronic illness. The benefits of respite care are outlined as follows: gives the family peace of mind, allows the family to enjoy favorite pastimes, improves the family's ability to cope with daily responsibilities, helps preserve the family unit, allows the family to become involved in community activities, allows the family to take a needed vacation, and makes it possible for family members to establish individual identities. The federal legislation impacting on respite care is reviewed and the funding problems are addressed. Suggestions are provided for parents on determining whether the family could benefit from respite care, locating respite care services, and asking the right questions to obtain essential information from service agencies. Contains a resource list of 9 references, 6 additional resources, and 18 organizations. (CR)

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ED 399 753

NICHCY

Interim Update — June 1996

Briefing Paper

Respite Care

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Raising a child with disability or chronic illness poses many challenges. As families meet these challenges, time off can become a necessity for the caretakers. In recent years, the growth of respite care services—short-term specialized child care—has begun to provide families with some temporary relief.

This Briefing Paper *is adapted from a 1989 NICHCY publication called "Respite Care: A Gift of Time." It discusses the emergence and diversity of respite care services, with particular emphasis on the benefits of respite care for families of children with disabilities or special health care needs. Tips and advice for parents who are seeking respite care are also presented. This issue concludes with a current listing of readings and organizations that can provide parents and others with additional information on the subject of respite care.*

The birth of a child with a disability or chronic illness, or the discovery that a child has a disability, has profound effects on a family. When parents learn that their child has a disability or special health care need, they begin a process of continuous, lifelong adjustment. Adjustment is characterized by periods of stress, and during this time, family members' individual feelings of loss can be overwhelming, shutting out almost all other feelings. Coping with uncertainty about the child's development may interfere with the parents' ability to provide support to each other and to other family members. Even when the diagnosis is clear, there are still many uncertainties — health, programmatic, and financial.

Social and community support can reduce the stress experienced by families. The support of relatives, friends, service providers, and the community can help families ease the adjustment period. Over the years, there has been a growing awareness that adjustment to the special needs of a child influences all family members. This awareness has generated interest and has led to the development of support services for families to assist them throughout the lifelong adjustment process. Within the diversity of family support services, respite care consistently has been identified by families as a priority need (Cohen & Warren, 1985).

The following was written by a parent of a child with a chronic illness.

Of the first six months of my child's life, three and a half months were spent in the hospital. We lived in a world of intensive care, with cardiac monitors, oxygen tents, tubes in every orifice and IV's in every extremity of my daughter's body.

The weeks my daughter was home were completely taken up with her care: two hours to get a meal in her, so for six hours a day I was feeding her; up many nights holding her

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so she could sleep on my shoulder so that she could breathe if she had a respiratory infection. Respiratory infections were frequent because of her disabilities, and many nights my husband and I would have to get our older child up, take him to our neighbor's house and take my daughter to the hospital where she could have oxygen if her breathing got too labored. After getting her admitted, we would go back home, and get up again the next morning to get our son off to school and to return to the hospital. This after being awakened in the middle of the night with a phone call from the hospital saying that they were transferring her to intensive care so she could be watched more closely.

Did we need respite? You bet we did! This was important particularly with a disabled and medically fragile child who needed expert care.

During that time, either my husband or I always had to be with our daughter while the other ran to the grocery, the bank, the pediatrician for our son's health care needs, or just to sleep for a few hours. Our friends disappeared from our lives, and our relatives lived far away. The world of normal family life in which family members live, work, and play together and take joy in each other's accomplishments, activities, and outings vanished.

Our daughter had major surgery scheduled at six months and she would be hospitalized for at least 10 days. I approached my daughter's doctors with our family's need for a rest. Would they and the nurses care for her for seven days while our family went away? We wouldn't leave for three days after surgery to make sure she was on the road to recovery. We felt safe leaving her in their hands, and we could truly relax.

The week that our family stayed at the beach was the most wonderful gift during those six months. It was truly a blessing, not only for us but for our daughter, for it gave us the opportunity to stand outside the situation and view it from a distance. It enabled us to review what had gone on before, to put things into perspective, to think and plan. We were also physically restored, and we were able to go on with much more strength for the next 12 months caring for our daughter. Respite care was unavailable 11 years ago when we needed to cope with the challenges my daughter presented to our family. I had to make it happen. Ω

All parents need a break now and then, to have time for themselves away from the responsibilities of caring for their children. This is true for families of children with disabilities or chronic health care needs too, only for these families it may be more difficult to arrange.

"Parents...are clearly the experts about the need and importance of respite care."

While respite may be a new word for some people, it is not a new phenomenon; it emerged in the late 1960's with the deinstitutionalization movement. One of the most important principles of this movement was the belief that the best place to care for a child with special needs is in the child's home and community. Families with a child who has a disability or chronic illness know the commitment and intensity of care necessary for their children. The level of dedication and care becomes part of daily life, part of the family routine, but this same commitment can make stress routine too. Parents can become accustomed to having no time for themselves. According to Salisbury and Intagliata (1986), "the need of families for support in general and for respite care in particular has emerged as one of the most important issues to be addressed in the 1980's by policymakers, service providers, and researchers in the field of developmental disabilities," (p. *xiii*).

Respite care is an essential part of the overall support that families may need to keep their child with a disability or chronic illness at home. United Cerebral Palsy Associations, Inc. (UCPA) defines respite care as "a system of temporary supports for families of developmentally disabled individuals which provides the family with relief. 'Temporary' may mean anything from an hour to three months. It may also mean 'periodically or on a regular basis.' It can be provided in the client's home or in a variety of out-of-home settings," (Warren and Dickman, 1981, p. 3). Respite services are intended to provide assistance to the family, and to prevent "burnout" and family disintegration. Since not all families have the same needs, respite care should always be geared to individual family needs by identifying the type of respite needed and matching the need to the services currently available, or using this information to develop services where none exist. Once identified, it is also important for families to have ready access to that type of respite, in an affordable form.

Regardless of the type of respite program utilized, the emphasis should be on orienting services toward the entire family. The birth of a child with a disability or the discovery that a child has a disability or chronic illness is obviously a difficult time for the entire family, including siblings, grandparents and other relatives. Families need to adjust to major changes in their daily lifestyles and in their dreams. Extended family and friends will also need to adjust to these changes. These changes will take planning and time. We are accustomed to typical family life; a child with a significant disability or chronic illness is not typical. Therefore,

plans for an untypical lifestyle call for creativity and flexibility. It is also important to bear in mind that the child will change as he or she grows and develops into an individual with his or her own personality and ideas.

Many families will find these changes difficult to handle. Many communities may be limited in their resources or in their interest in meeting the special needs such families present. These combined factors can leave the immediate family with the full-time care of their child and can lead to feelings of isolation from other family members, friends, community activities, religious and social functions. Even performing the basic necessities of daily life, such as grocery shopping or carpooling, can become difficult to impossible.

It is obvious to anyone who has lived this life that respite care becomes a vital service—a necessity, not a luxury. Parents, of course, are clearly the experts about the need and importance of respite care. Just as families differ, so will the necessity for respite care. Basically, however, all families require some relaxation, diversion, and the security of knowing that their children are safe and happy. The most difficult problem for the family with a child who has a disability is finding the quality of care and expertise the child needs.

As one parent put it, "Families need an uncomplicated, easily accessible means of arranging respite care to suit their wants and needs. When a potential pleasure becomes more trouble than it's worth, then I give it up. I always measure the event against the complications involved in making it happen. Time off is no relaxation if I spend the entire time worrying if the kids are OK. I can't enjoy myself if I think they are unhappy, and certainly I can't relax if I'm not confident about the reliability of the person watching my children. I think many professionals are under the misconception that time away from the cares of rearing a child with a disability is what I need to maintain my sanity. I need much more than time—I need the security that comes from *knowing* that the person I've left my son with is as capable as I am of providing for his needs. You simply can't relax and enjoy yourself and worry at the same time. It's peace of mind I need — not just time."

"The child or youth with a disability also benefits from respite care, gaining the opportunity to build new relationships and to move toward independence."

Benefits of Respite Care

In addition to providing direct relief, respite has added benefits for families, including:

Relaxation. Respite gives families peace of mind, helps them relax, and renews their humor and their energy;

Enjoyment. Respite allows families to enjoy favorite pastimes and pursue new activities;

Stability. Respite improves the family's ability to cope with daily responsibilities and maintain stability during crisis;

Preservation. Respite helps preserve the family unit and lessens the pressures that might lead to institutionalization, divorce, neglect and child abuse;

Involvement. Respite allows families to become involved in community activities and to feel less isolated;

Time Off. Respite allows families to take that needed vacation, spend time together and time alone; and

Enrichment. Respite makes it possible for family members to establish individual identities and enrich their own growth and development.

Often, we hear the question, "Who takes care of the caretakers?" Caretakers can include not only parents, but also brothers and sisters, grandparents, and extended family and friends. Respite gives caretakers the opportunity to have a rest, to take care of personal matters, to enjoy some leisure time, and occasionally to be relieved of the constant need to care for a child with a disability or chronic illness.

The child or youth with disabilities also benefits from respite care, gaining the opportunity to build new relationships and to move toward independence. In many families, it is common for children to attend day care or after-school care, interact with peers and adults outside the family, and stay with a child care provider while their parents enjoy an evening out. Respite provides these same opportunities for children with special needs.

For older individuals with a disability, respite can assist in building skills needed for independent living. Since the most appropriate living situation for many adults with a disability is in a group home or other supported environment, out-of-home respite care can

enable families to test this option, explore community resources and prepare themselves and their family member with a disability for this change.

States and communities are recognizing that respite care also benefits them. On average, the costs for respite services are 65 to 70 percent less than the costs of maintaining people in institutions (Salisbury and Intagliata, 1986). The cost-effectiveness of respite services allows scarce tax dollars to be used for additional community-based services. During the previous decade, over 30 states passed legislation for in-home family support services, including respite care, using either direct services or voucher systems (Agosta and Bradley, 1985).

With the 1986 passage of the Children's Justice Act (Public Law 99-401) and its amendment, the Children's with Disabilities Temporary Care Reauthorization Act (P.L. 101-127), respite care has gained support at the Federal level. This legislation authorized funding to states to develop and implement affordable respite care programs and crisis nurseries. Unfortunately, while this Federal funding provides relief for some families, access and affordability continue to be issues for many families in need. As Brill (1994) observes:

> Families soon discovered that the law fell short of providing national guidelines for respite care. Every state dispensed different versions of the services, and individual agencies devised their own criteria for length of time and funding allotments. (p. 49)

Thus, in spite of the availability of government funding in some areas, many respite care programs must charge for their services. This practice reduces expenses for providers and makes it possible to serve more families. However, charging for respite services can limit their availability to those families who can afford the fees (Cohen and Warren, 1985).

For children and youth with disabilities, their families and communities, and Federal, state and local governments, the benefits of respite care are enormous. However, the need for maintaining and expanding the levels of available respite services is tremendous.

"In spite of the availability of government funding in some areas, many respite care programs must charge for their services. This practice reduces expenses for providers and makes it possible to serve more families."

Respite Care Suggestions for Parents

Parents deciding to leave their child who has special needs in the care of someone else, either in or outside their home, may experience a variety of hesitations. They can have feelings of guilt, anxiety, even a sense of loss of control.

Jeanne Borfitz-Mescon (1988) suggests that a number of fears and concerns are common to parents in this situation: that the child may not get as much attention, or that the care may not be as good; that something may be missed; that the caretaker or staff may not be able to comfort their child, and that he or she might be left crying. The anxiety resulting from these very normal and real concerns or fears can in fact cause parents to believe that respite is just not worth it.

It is important that as a parent you become comfortable with your decision and develop the trust critical to maintaining the peace of mind necessary for relaxation and enjoyment. One way to accomplish this goal is to begin now to think about respite care and whether you, your family, and your child with special needs would benefit from it. The following suggestions may help.

How can you tell if your family could benefit from respite care?

Ask yourself the following questions:

1. Is finding temporary care for your child a problem?
2. Is it important that you and your spouse enjoy an evening alone together, or with friends, without the children?
3. If you had appropriate care for your child with special needs, would you use the time for a special activity with your other children?
4. Do you think that you would be a better parent if you had a break now and then?
5. Are you concerned that in the event of a family emergency there is no one with whom you would feel secure about leaving your child?
6. Would you be comfortable going to a trained and reputable respite provider to arrange for care for your child?

If you have answered "Yes" to several of these questions, you and your family could benefit from respite care and should investigate the resources in your community.

Many agencies and organizations have information on respite care services. (For a referral, contact the National Respite Locator Service, operated by the ARCH National Resource Center: 1-800-773-5433). In general, seek out groups or professionals who work with children your child's age. For example, if your child is in preschool, contact the school and discuss the need for respite care with the staff. If there is a parent group associated with your school, or if there is a local parent group concerned with children who have needs similar to your child's, ask them. If your child is an adolescent, talk to the staff at his or her school or, again, identify parent groups in your area with needs similar to yours.

The following list presents some of the types of groups you may want to contact in seeking services. Many will be listed in your telephone book. If you experience difficulty locating the organization in your community, often a state contact can be made. For further information and assistance, contact NICHCY, and be sure to ask for a NICHCY *State Resource Sheet* for your state. Additional resources are listed at the end of this *Briefing Paper*.

State and Local Government Agencies

- State Department of Mental Retardation
- State Developmental Disabilities Council
- State Program for Children with Special Health Care Needs (formerly Crippled Children's Services)
- Departments of Health and Human Services, or Social Services
- Department of Mental Health
- State and local Departments of Education
- State Protection and Advocacy Agency

State and Local Disability or Support Groups

- The Arc
- United Cerebral Palsy Associations, Inc.
- Autism Society of America
- Brain Injury Association
- Mental Health Association and CASSP
- Spina Bifida Association
- National Easter Seal Society
- Parent Training and Information Center
- Parent-to-Parent
- University Affiliated Program(s)
- Community Services Board
- YMCA/YWCA
- Churches
- Recreation Centers

What should you know when seeking respite care services in your community?

Ask yourself the following questions. The information will be helpful to you when contacting agencies in your local community about respite care (Bradley, 1988).

1. What kind of services do I need? (Long-term, short-term, or both? Why?)
2. Do I prefer services in my home, a cooperative, or in an outside setting? (This will depend on the type of service you need.)
3. Can I donate my time to a cooperative, or is it better for me to obtain help from a respite agency?
4. Does this agency provide the types of service I need?
5. Is there a cost for the service?
6. Am I able to afford this service?
7. If I can't afford the service, are there funds available to assist me?
8. Who is responsible for the direct payment to the provider?
9. How are respite providers selected?
10. Are the providers trained?
11. How many hours of training have they had?
12. Do these providers have training in First Aid and CPR?
13. What other areas are covered in their training?
14. For out-of-home care, does anyone monitor the facility for safety and health measures?
15. Will I be able to have a prior meeting with the care provider?
16. Will I have an opportunity to provide written care instructions to the provider?
17. Will I have an opportunity to assist in training the provider with reference to my son's/daughter's needs?
18. What is the policy that covers emergency situations?
19. Will I have to carry additional insurance to cover the provider while he/she is in my home?
20. Is there a policy which deals with mismatches between providers and the family?
21. Can I request a specific care provider and have the same person with my child each time?
22. Will the respite care provider care for my other children too?

A Final Word...

Caring for a child with disabilities or severe health problems can be a full-time job. It is easy to become overwhelmed with the care needs of a child with a disability or chronic illness. Often, families who would not hesitate to call for relief from the constant care of their typical children hesitate to call for relief from the care of their child with a disability or special health care need. That is why respite, as the word implies, is truly an interval of rest. Respite can be your answer to renewed energies and a new perspective. If respite care is not available in your community, make it happen. The best advocate for your family and your child is you. One of the most important goals to strive for is family unity and well-being. It is important to remember that you, too, can have the gift of time that respite care represents.

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Additional Resources

ARCH National Resource Center. (1995). *ARCH national directory of crisis nurseries and respite care programs.* Chapel Hill, NC: Author. (Available from ARCH National Resource Center, Chapel Hill Training-Outreach Project, 800 Eastowne Drive, Suite 105, Chapel Hill, NC 27514. Telephone: 1-800-473-1727; (919) 490-5577.)

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Kniest, B.A., & Garland, C.W. (1991). *PARTners: A manual for family centered respite care.* Lightfoot, VA: Child Development Resources; Richmond, VA: Virginia Institute for Developmental Disabilities, Virginia Commonwealth University, Respite Resource Project. (Available from Respite Resource Project, at the address listed above.)

Organizations

CLEARINGHOUSES AND TECHNICAL ASSISTANCE:

ARCH National Resource Center for Crisis Nurseries and Respite Care Services — Chapel Hill Training-Outreach Project, 800 Eastowne Drive, Suite 105, Chapel Hill, NC 27514. Telephone: (800) 473-1727; (919) 490-5577. The mission of the ARCH National Resource Center is to provide support to service providers through training, technical assistance, evaluation, and research. The Center provides a central contact point for the identification and dissemination of relevant materials to crisis nurseries and respite care programs. Numerous fact sheets and general resource sheets (including state contact sheets) are available about respite care and crisis nursery care. ARCH also operates the National Respite Locator Service who's mission is to help parents locate respite care services in their area. Please contact them at 1-800-773-5433.

OTHER ORGANIZATIONS:

The Arc (formerly the Association for Retarded Citizens of the United States) — 500 E. Border Street, Suite 300, Arlington, TX 76010. Telephone: (800) 433-5255; (817) 261-6003; (817) 277-0553 (TT).

Association for the Care of Children's Health (ACCH) — 7910 Woodmont Avenue, Suite 300, Bethesda, MD 20814. Telephone: (800) 808-2224; (301) 654-6549.

Association for Persons with Severe Handicaps (TASH)— 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204. Telephone: (410) 828-8274; (410) 828-1306 (TT)

Autism Society of America — 7910 Woodmont Avenue, Suite 650, Bethesda, MD 20814. Telephone: (800) 3-AUTISM; (301) 657-0881.

Brain Injury Association (formerly the National Head Injury Foundation) — 1776 Massachusetts Avenue N.W., Suite 100, Washington, DC 20036. Telephone: (800) 444-6443; (202) 296-6443.

Epilepsy Foundation of America — 4351 Garden City Drive, Landover, MD 20785. Telephone: (800) 332-1000 (outside of MD); (301)459-3700.

National Down Syndrome Congress — 1605 Chantilly Drive, Suite 250, Atlanta, GA 30324. Telephone: (800) 232-6372; (404) 633-1555.

National Down Syndrome Society — 666 Broadway, New York, NY 10012-2317. Telephone: (800) 221-4602; (212) 460-9330.

National Easter Seal Society — 230 West Monroe Street, Suite 1800, Chicago, IL 60606. Telephone: (800) 221-6827; (312) 726-6200; (312) 726-4258 (TT).

Sick Kids (need) Involved People (SKIP) — 545 Madison Avenue, 13th Floor, New York, NY 10022. Telephone: (212) 421-9160.

Spina Bifida Association of America — 4590 MacArthur Boulevard N.W., Suite 250, Washington, DC 20007. Telephone: (800) 621-3141; (202) 944-3285.

United Cerebral Palsy Associations, Inc. (UCPA) — 1660 L Street N.W., Suite 700, Washington, DC 20036. Telephone: (800) 872-5827; (202) 842-1266.

Zero to Three/National Center for Clinical Infant Programs — 734 15th Street, NW, Suite 1000, Washington, DC 20005-1013. Telephone: (202)638-1144. (Voice); 1-800-899-4301 (Publications).

FAMILY SUPPORT PROJECTS:

American Association of University Affiliated Programs (AAUAP) — The AAUAP represents the national network of University Affiliated Programs (UAPs) in the United States. The UAPs provide interdisciplinary training for professionals and paraprofessionals and offer programs and services for children with disabilities and their families. Individual UAPs have staff with expertise in a variety of areas and can provide information, technical assistance, and inservice training to agencies, service providers, parent groups, and others. For information on a UAP in your area, write: AAUAP,8630 Fenton Street, Suite 410, Silver Spring, MD 20910. Telephone: (301) 588-8252.

The Beach Center on Families and Disability — This center conducts research and training, and disseminates information relevant to families who have members with developmental disabilities or serious emotional disturbances. Write: The Beach Center on Families and Disability,The University of Kansas, 3111 Haworth Hall, Lawrence, KS 66045. Telephone: (913) 864-7600.

Children and Adolescent Service System Programs (CASSP) — CASSPs are federally-funded programs located throughout several states and localities, designed to improve service delivery for children and adolescents with emotional disorders. CASSP provides funding to states for research and training centers and for technical assistance activities. To contact a CASSP in your area, or to obtain a publications list and additional information, write: National Technical Assistance Center for Children's Mental Health, 3307 M Street, NW, Suite 401, Washington, DC 20007. Telephone: (202) 687-5000.

National Clearinghouse on Family Support and Children's Mental Health — The Center provides research and training, and disseminates information relative to serious emotional disorders and family support issues, including a newsletter. Write: National Clearinghouse on Family Support and Children's Mental Health, Portland State University, P.O. 751, Portland, OR 97207-0751. Telephone: 1-800-628-1696; (503) 725-4040.

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